Health Information Privacy: Technologies, Users and Institutions

Main objective and summary of the project

The digitalization of patient information and the proliferation of health information sharing across systems, organizations and national borders require new knowledge and practices to ensure patient privacy, security and confidentiality. This is a particular challenge in developing countries where relevant regulations and legal frameworks are often lacking or outdated; skills to assess the impact of new (digital) technologies and address them are scarce; and organizational routines for appropriate handling of sensitive information are not institutionalized. Hew digital technologies such as mobile Internet, cloud computing and smartphones are challenging patient privacy, security and confidentiality. This PhD-project aims to contribute to research on patient information privacy in developing countries by participating in ongoing activities at the Department of Informatics geared at strengthening health information systems.

The Health Information System Program at UiO (HISP; see http://hisp.uio.no) is situated with the Information Systems research group (http://www.mn.uio.no/ifi/english/research/groups/is/) and has for more than two decades developed, maintained and supported the implementation of the DHIS2 software (see http://dhis2.org). The DHIS2 has over the last few years expanded in scope from only supporting the collection, aggregation and visualisation of routine health statistics, to include software modules that allow for identification and follow-up of individual patients enrolled in health programs including child immunization and adherence to HIV and Tuberculosis treatment regimens (ART). As an action-research program, the DHIS2 has always been developed in close collaboration with its users in developing countries and with a focus on supporting and serving the needs of health care workers and managers. This project will be located within the DHIS2 core software development and implementation team at UiO; software partners in e.g. Vietnam, India, Tanzania and Uganda; implementation partners in developing countries and other NGOs; Ministries of Health; and other partners (including e.g. WHO, The Norwegian Institute of Public Health etc.). The project will be focused on building a better understanding of key patient privacy concerns related to health information systems in developing countries while at the same time assure that DHIS2 is adhering and promoting patient privacy. An important aspect of this will be knowledge sharing and capacity building in developing countries.

DHIS2 is currently used across more than 50 countries in Africa, Asia and Latin America, and in many of them as a national health data warehouse. To support DHIS2 implementations and build the capacity for its use, HISP UiO is collaborating with a range of global organizations, including UNICEF, the Global Fund to fight AIDS, Tuberculosis, Malaria (Global Fund), and the Centre for Disease Control (CDC) and the United States President's Emergency Plan for AIDS Relief (PEPFAR). HISP UiO is also established as a collaborating centre of the World Health Organization (WHO).

Project background and scientific basis

Given the increasing adoption of DHIS2 to support patient management, there is an urgent need for developing good support for patient privacy. Our overarching academic domain is that of ICT for development. Specifically, the research will take place within a context of distributed open source

software development[1], where generic solutions are sought over specific ones[2] and the ultimate aim is to establish and maintain DHIS2 as a Global Public Good. The increasing gap between the generic software and specific implementations on a global scale is approached through multiple strategies, most notably long-term institutional capacity building[3].

Our vibrant Information Systems research group consists of 7 Professors, 2 Associate Professors, 2 Adjunct Professors, 4 Postdoc researchers, 30+ PhD-students as well as Master students. Under the supervision of HISP UiO, 90 full time employees are involved in the development and implementation of DHIS2 globally.

Research Questions and Scientific Challenges

Depending on the background and core interest of the candidate, the project will be related to technical aspects of the DHIS2 software (e.g. security of Android clients or server configuration and management), development and implementation of health information governance procedures and capacity building needed to address these issues in developing countries. More concrete research focus areas will be developed together with the supervisors and can be, but are not limited to;

- General policy on privacy for the global HISP network and for countries using DHIS2
- Mobile ICTs and privacy concerns in health services
- Cloud hosting, server maintenance, and privacy
- Responsibility and accountability around privacy and confidentiality when many actors are involved in the development, implementation, maintenance, and evolution of DHIS2 in countries
- Global public goods and privacy

Research Approach

Moving from aggregated to patient based data and with its increasing footprint, DHIS2 is confronted with new requirements for information privacy, security and confidentiality. With its basis in the global DHIS2 community, this PhD project will be practice-oriented and involved in the analysis of DHIS2 related privacy concerns. The candidate will participate in the development and implementation of important recommendations, standards and guidelines for patient privacy, security and confidentiality. The right candidate will have a background in information systems, computer science or public health, and have a passion for patient privacy. We will appreciate candidates with a multidisciplinary background, also related to other disciplines than listed above. The project will aim at contributing both to research in the field of information systems, and to strengthen the DHIS2 software and implementations by contributing to patient privacy.

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[1] Titlestad, O., Staring, K. and Braa, J. (2009). "Distributed Development to Enable User Participation: Multilevel Design in the HISP Network." *Scandinavian Journal of Information Systems* 21, no. 1.

[2] Gizaw, A., Bygstad, B. and Nielsen, P. (2016). "Open Generification." *Information Systems Journal*

[3] Braa, J., Monteiro, E. and Sahay, S. (2004)."Networks of Action: Sustainable Health Information Systems across Developing Countries." *Management Information Systems Quarterly* 28, no. 3

Ethics

The project will notify the Norwegian Social Science Data Services (NSD) and adhere to the guidelines of relevant Research Ethical Committees in other countries were fieldwork will be conducted. Indeed, a major component of the research is related to ethics of collecting and storing patient data, and working in close collaboration with Ministries of Health around the world the project aims at setting ethical considerations around patient records and digital systems high on the agenda in the respective countries.

Project timeline

2017:Q4	Planning, literature review, and identifying relevant privacy issues	2020:H1	Fieldwork, publication, teaching
2018:H1	Coursework, fieldwork, teaching	2020:H2	Fieldwork, publication
2018:H2	Coursework, fieldwork, first publication	2021:H1	Publication, write up
2019:H1	Fieldwork, publication, teaching	2021:Q3	Write up and defend
2019:H2	Fieldwork, research stay abroad, publication		